

TESTIMONY

BEFORE THE

SENATE COMMITTEE ON FINANCE

SUBCOMMITTEE ON HEALTH

ON

THE MEDICAID PROGRAM AND LONG TERM CARE SERVICES

FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

RESPECTFULLY SUBMITTED

BY

UNITED CEREBRAL PALSY ASSOCIATIONS, INC.

WITNESS:

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JANESVILLE, WISCONSIN

FRIDAY, SEPTEMBER 19, 1986

## SUMMARY

o Representing UCPA today | is Jeff Gunderson of Janesville, Wisconsin. Mr. Gunderson, a former ten-year, resident of a Medicaid funded nursing home who today lives in a HUD subsidized apartment with a full-time attendant, is testifying on behalf of thousands of persons like himself who meet the Medicaid ICF/MR eligibility criteria for "related condition" to mental retardation and continue to reside in restrictive settings which are not cost effective in the use of either human or financial resources.

o Based on his personal experiences and those of UCPA affiliates over the past twenty years, we offer the following recommendations for reshaping Medicaid financial policy to promote community, integrated services: 1) Redefine the ICF/MR as a program for persons with developmental disabilities to provide family and community residential services and comprehensive, long term, personalized support services; 2) Establish as the goals of the program, increased individual independence, productivity, and community integration as defined in the Developmental Disabilities Act of 1984; 3) Provide an assurance that all individuals with mental retardation or a "related condition" are eligible for such long term personalized support services including, at a minimum: a) an assessment of functional needs for eligibility; b) the convening of an interdisciplinary team to prepare a comprehensive individualized plan of services leading to the above stated outcomes; c) the assignment of a case manager who is independent of the provider system; and d) the person's freedom to choose service models and providers with procedural safeguards; and 4) Provide the states greater flexibility to meet individual needs by: reducing burdensome process/paper regulations; increasing the accountability of states and providers for having trained, competent staff; assuring that individuals benefit from services by achieving measured increases in functional independence, productivity, and community integration; allowing the states to provide a full array of services similar to the Home and Community Care Waiver including individualized family support services and supported employment; and increasing the federal reimbursement by 5% for small community living arrangements and comprehensive support services and reducing the federal reimbursement by 5% for any congregate care and institutional services.

INTRODUCTION

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Thank you Mr. Chairman for the opportunity to speak with you today about Medicaid funds for long-term-care for persons with developmental disabilities.

My name is Jeff Gunderson. I live in Janesville, Wisconsin. I am testifying today on behalf of myself and United Cerebral Palsy Associations, Inc. UCPA is a national network of 220 private, nonprofit agencies in 45 states. We are linked by a common objective—providing appropriate services to and advocating for the needs of persons with cerebral palsy and other individuals with similar severe disabilities.

You have had the opportunity this morning to listen to national experts in the field of developmental disabilities, federal officials, and state and local administrators of human service programs. You have heard a great deal about costs, spending trends, and statistics. I am one of those statistics—an individual whose life was affected by the so called "institutional bias" of Medicaid.

Today I want to do two things. First, I want to share with you my experience and the experience of two other individuals with developmental disabilities and second, I want to give you some recommendations for changes in Medicaid policy. REAL LIFE EXAMPLES

None of the three of us are mentally retarded. Our disabilities result in substantial functional limitations in several areas of major life activity such as mobility, self-care, and economic self-sufficiency. We meet the test of eligibility for "related conditions" under Title XIX for provision of services in the ICF/MR program. Despite being eligible for services in this program, the majority of states have ignored the needs of people like us unless we also have a diagnosis of mental retardation.

Let me tell you about Jack. He was born with cerebral palsy. When he was four years of age, his parents were unable to cope with his needs. At the recommendation of their family physician, they placed Jack in a state institution. Although of above average intelligence, Jack remained in the large state facility for 21 years. As part of a so-called "deinstitutionalization" mandate resulting from a court decree, Jack was placed in a nursing home where he has resided for the past 10 years. Jack is 35 years old. His co-residents average over 70 years of age. Jack moves about in an electric wheelchair and communicates with staff with a portable voice activated computer. The computer was purchased by staff as a result of their own private contributions. It was not paid for by the "system". There are no planned activities, and most of Jack's time is spent following the staff around the facility.

Jack is not sick! He is not in need of nursing or medical care which are the primary services provided by the nursing home. The only reason Jack lives in a large intermediate skilled nursing facility subsidized by Medicaid is that the personal attendant services he needs are not paid for under Title XIX in his community. Jack told staff at the UCP of Detroit, "I want a way out". Unfortunately, Jack must continue to reside in a restrictive and inappropriate setting for at least three more years before an accessible apartment and personal support services may be available. I don't believe this is an effective or efficient use of our financial or our human resources.

Let me tell you also about Karen. She has cerebral palsy and used to walk with a walker, but is now in a wheelchair. Karen went to school until she was 18, and has lived at home ever since. She is now 37 years old and lives with her parents who are 65 and 67 years old. They cannot continue to lift their daughter out of bed, to dress her,

to put her in their car, and they don't know how much longer they will live. They have been advised to place her in a nursing home or institution, but have heard of bad experiences in those facilities. Her parents, who live in a remote desert area of California, wrote recently to the UCPA national office seeking an answer in terms of their daughter's current and future long-term support service needs. No other options are available to Karen and her family in their home community I

Let me tell you about Jeff Gunderson. I lived with my parents until I was 18, and attended the public schools. When my parents got divorced, it was too much of a struggle for my mother to keep me, and I was placed in a nursing home. My mother was not offered any support services as an alternative so that I could remain at home.

Five years ago yesterday, I moved out of the nursing home into my own apartment with full-time attendant support services. And that almost didn't happen because many professionals think you have to go through a "continuum" of places like group homes before you can live in an apartment. How silly. I'm here to tell you that people like me need support services and a decent place to live in the community, like everyone else. We don't need to go through four to six less and less restrictive "facilities" in order to graduate to an apartment. In fact, if UCP of Wisconsin and our Wisconsin Developmental Disabilities Council had not committed money to try this approach, I'd probably still be in the nursing home.

I don't like thinking about the ten years I spent in the Medicaid funded nursing home. It was awful. I felt lost and forgotten. I had nothing in common with the people I lived with. Most of the other residents were elderly or mentally retarded and physically handicapped. When people my age in the community are just starting to

have a good

time, we in institutions are all getting ready for bed. I was considered a behavior problem because I didn't want to go to bed at seven o'clock. My punishment for not complying was a cold shower--very painful for someone like me with spastic muscles. I lived in a nursing home even though I am not sick, don't need nursing or medical services, and don't want to be dependent. Even though I have some friends back at the nursing home, I don't like going back to visit.

Today, I live in an apartment subsidized by HUD funds. My full-time attendant, who provides me assistance in dressing, bathing, and eating, is supported by my SSI and state funds. Until I had a chance to live on my own, I didn't know what I was missing. I had been deprived of common life experiences so many people take for granted.

This is the first time I have ever been to Washington, D.C. Yesterday was the first time I ever flew on an airplane. Although I am more than a little nervous, I wanted to come here today to testify on behalf of all persons with severe physical disabilities who, like myself, were deprived and continue to be deprived of the opportunity to be more independent. My serious physical disabilities hide from others my real capabilities to make choices and enjoy living. MEDICAID

Medicaid is an entitlement program. It shares fiscal responsibility with the states for the "long-term-care" needs of persons with developmental disabilities. More than 15 years ago, the ICF/MR program was added to ensure that persons like me are provided a certain level of care that includes active treatment--not a living death!

In 1985, Medicaid spent \$14.7 billion for nursing home care, more than one-third of total Medicaid spending. In several states, nursing home payments account for almost two-thirds of the state's Medicaid budget.

The range of services needed by persons with developmental disabilities is as diverse as the population in need. There is a need for a full array of personal, individualized health, social, habilitation/rehabilitation, and personal support services over an extended period of time.

Long-term-care services can be provided in a variety of settings — at home, in the community, and within institutions. Unfortunately, only one dollar of every four that Medicaid expends on long-term-care services for persons with disabilities is spent in a home or small community setting.

I live in my own apartment. Each day of the week, my attendant assists me with bathing, eating, dressing, and getting around our community. I enjoy my freedom; an array of support services made possible by federal and state financing that costs about 25 per cent less on a monthly basis than what it costs the federal Medicaid program for custodial care in a nursing home where you have no sense of personal worth and dignity. CONCLUSIONS BASED ON UCPA'S SERVICE EXPERIENCES

UCP has been providing community, residential, and support services in forty states for over twenty years. Based on our experience, the following conclusions have been reached:

- 1) The continuing institutional bias of Medicaid in the ICF/MR program fails to respond to individual needs by rewarding states for the use of congregate care, facility based services for persons with developmental disabilities: young children are denied their right to grow up in a family; adults with severe disabilities are denied the freedom of choice as to where they can live.



- 2) The strict interpretation of HHS that limits the definition of habilitation services to pre-vocational activities deprives thousands of persons with developmental disabilities the opportunity to become more independent, productive, and partially self supporting tax payers;
- 3) Almost no one with developmental disabilities needs to be in an institution, because for each individual in a Medicaid funded large institution, there is an individual with virtually identical disabilities and levels of service need now living successfully in a community setting;
- 4) The overall cost of individualized home and community services is equal to or less than the group cost of providing comparable services to individuals with similar levels of need in an institutional setting;
- 5) Families who have struggled and sacrificed to keep their son or daughter at home are now being penalized for their efforts. The Home and Community Care Waiver primarily targets those individuals who have been institutionalized for new community services and places individuals living at home on the longest waiting list for such services; and
- 6) The primary reason persons with developmental disabilities are not able to remain in their natural home or a real home of their own choice is the failure of Medicaid to reimburse for an array of personal support services except under a limited Home and Community Care Waiver.

## SERVICE PRINCIPLES

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UCPA believes Medicaid public policy has not kept pace with the current state of knowledge and best practice for effective service delivery for persons with developmental disabilities. Recently, UCP of Indiana adopted the following set of principles to guide future service planning and development:

Services must be available to persons living in their natural home or a home of their choice. Relocation must not be a necessary condition to access services. Services and funding must be available and follow persons with disabilities regardless of the setting.

Services must be provided based on individual needs, not related to restrictions of specific funding services. The provision of services must not be based on the availability of services.

Service goals must be directed toward physical and social integration in one's own community. Services must be delivered in a manner which uses positive interventions and promotes enhanced images and valued social roles of service recipients.

- Services must utilize and foster the development of community generic resources. (Training must focus on acquiring functional, useful skills and using community resources.) Services must minimize the need for skill transfer by providing training in the environment in which the skills are required.

- Services must respect personal preferences and desires of those served. Services must maximize the autonomy and independence of consumers. Multiple options/providers must be available to individual consumers in each service category.
- Service recipients must participate in the planning, operation, and evaluation of services. Services should maximize the participants self-direction and control leading toward self-governance.

Service recipients must be supported in a life style and setting of their choosing and typical of their peers. Services must assist residents in participating in community activities with non-disabled peers. Services must utilize the least restrictive environment in which needed supports can be provided.

Priority for services must be given to persons with more severe disabilities who have greater support needs. Services must be flexible to provide a variety of support options in varying intensity according to each individual's needs. Residential support services must be coordinated with all other service components including, but not limited to; employment, social and transportation.

#### RECOMMENDATIONS

The well intentioned Medicaid long-term-care program for persons with developmental disabilities, begun in 1971, has become entrenched. We now have an outmoded, ineffective, inefficient service model being reinforced and expanded with a public policy of federal financing. You have the power to stop this trend today and bring the Medicaid program

into harmony with all other congressional mandates concerning persons

with disabilities such as those articulated in: 1) the Education for All Handicapped Children's Act of 1975 (P.L. 94-142); 2) the Rehabilitation Act of 1973 and current amendments now in conference committee for reauthorization including a major commitment to employability and integrated, supported employment rather than sheltered workshops for persons with severe disabilities; and 3) the Developmental Disabilities Act of 1984 (P.L. 98-527) with a declaration that all services to persons with developmental disabilities should result in the measurable outcomes of increased independence, productivity and community integration.

UCPA commends Senators Chafee, Weicker, and Bradley for the respective pieces of legislation they have introduced to reshape Medicaid policy in concert with these other landmark laws of our country.

As William Shakespeare said, we must "suit the action to the words." We urge you to begin Medicaid financial policy redirection today by considering the following amendments to current Medicaid law through the Budget Reconciliation Act in Conference Committee.

1. Redefine the ICF/MR as a program for persons with developmental disabilities to provide family and community residential services and comprehensive, long term, personalized support services;
2. Establish as the goals of the program, increased individual independence, productivity, and community integration as defined in the Developmental Disabilities Act of 1984;

3. Provide an assurance that all individuals with mental retardation or a "related condition" are eligible for such long term personalized support services including, at a minimum:
  - o an assessment of functional needs for eligibility;
  - o the convening of an interdisciplinary team to prepare a comprehensive individualized plan of services leading to the above stated outcomes; o the assignment of a case manager who is independent of the provider system; and o the person's freedom to choose service models and providers with procedural safeguards;
4. Provide the states greater flexibility to meet individual needs by:
  - reducing burdensome process/paper regulations;
  - increasing the accountability of states and providers for having trained, competent staff;
  - assuring that individuals benefit from services by achieving measured increases in functional independence, productivity, and community integration;
  - allowing the states to provide a full array of services similar to the Home and Community Care Waiver including individualized family support services and supported employment; and
  - increasing the federal reimbursement by 5% for small community living arrangements and comprehensive support services and reducing the federal reimbursement by 5% for any congregate care and institutional services.

Please do not let another three and one half years go by where nothing has changed and 75% of the Medicaid dollars continue to support dependence, regression, and segregation. I urge you to act today on behalf of thousands of people with developmental disabilities who want the opportunity to become independent and to live, work, and recreate in the real community. Let us create a policy that assures human resource development and does not hold people back from life.

Thank you.